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Exploring Barriers: An Analysis of Access to Effective Tuberculosis Care in Cape Town

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Abstract

My independent study project (ISP) examines factors that hinder access to tuberculosis (TB) healthcare and its effective implementation in Cape Town. In order to expand research on the topic, important barriers will be examined and explained. This project is relevant due to the high prevalence and mortality rates of tuberculosis in South Africa, as well as the fact that an overwhelming emphasis on HIV can lead to overlooking the serious nature of TB as a public healthcare issue. It is hoped that this study will provide more insight into improving access to TB care, and be a resource for those who may not know about the common barriers. Furthermore, the existing competition between HIV/AIDS and tuberculosis in gaining the public health spotlight will be examined, specifically in relation to the effects of grouping the two ailments together under an umbrella of treatment adherence.

To carry out the study, various health care professionals, NGOs (Non-governmental organizations), and individuals in the city who had experience with TB were interviewed and asked their informed opinions of the top reasons behind inadequate access to TB care. This was supplemented by observation at two clinics, and attendance at a tuberculosis seminar at a local medical school.

This information was analysed and synthesized into a comprehensive explanation of the most prevalent factors which are: stigmatization, the role of traditional healers, socioeconomic factors, and public health issues. All these factors were found to affect diagnosis and treatment adherence. Participants also communicated possible solutions as: government assistance, education, and enhancement of public health services. This study communicates the impact of TB care disparities and relates to other disparities that influence South Africa.

Introduction

Mycobacterium tuberculosis or TB is the deadliest infectious disease that can be cured (Dye, C., 2006). The bacteria can be transmitted through the air in an infected person's sputum when they cough, making it particularly easy to contract and spread. Tuberculosis is a highly contagious bacterial infection that often starts in the lungs but may travel throughout the body to the brain and the spine, through the lymph system (Dye, C., 2006). This deadly disease may lie dormant in those that are exposed to the bacteria and only show symptoms when one's immune system is weakened. The World Health Organization (WHO) had been working on containing the disease long before its resurgence in 1993. South Africa is in the top 5 countries in the world in terms of number of active TB cases. The country also is marked by the WHO as one of the 22 high risk countries for tuberculosis and multi drug resistant tuberculosis (WHO, 2014). Doctors, scientists and epidemiologists are all working to try and regain control of the disease. The close study and analysis of tuberculosis is needed in order to help get the disease under control.

Many have discussed barriers in access to TB health care in South Africa and across the globe, and programs have been put into place to try and break down these barriers. However, the burden of the disease has persisted over the years suggesting that there is room for further research on why those with TB are not getting effective treatment or any treatment at all, and why the disease is not at bay. This paper will explore the impact and treatment of the disease in the densely populated city of Cape Town. There are many factors that play a role in access to effective care including not limited to stigmatization, public awareness, socioeconomic factors, patient treatment adherence, and drug availability. Exploring these factors by looking through the lens of those that work with or have been influenced by TB health care in this area may reinforce these known barriers to efficient care and hopefully help uncover new hindrances.

Uncovering the TB problem in Cape Town can help shed light on gaps in access to health care on a grander scale. More specifically, those who have HIV/AIDS are more susceptible to getting infected with tuberculosis due to the weakened immune system allowing for opportunistic infection and an increased rate of latent TB progressing to active TB (Pawlowski, Jansson, Sköld, Rottenberg, & Källenius, 2012). This is especially important for South Africa because South Africa has one of the highest numbers of people living with HIV and AIDS. Additionally, about 62% of those infected with tuberculosis are also HIV positive (WHO, 2014). Increasing awareness to barriers in access to TB care can also improve the healthcare for HIV/AIDS and other infectious diseases that are affecting South Africa. Through efforts of extensive medical research, public health policy institutions, and infrastructure improvements, the development and implementation of more preventative measures and effective treatments can help get the disease under control.

This ISP will start out by examining the barriers in access to care as assed by primary sources and current literature. The findings will be dissected and I will include my own personal interpretations guided by the research. Lastly, possible solutions to these barriers will be communicated, as assessed by the interviewees, literature research, and personal interpretation.

Limitations

I was able to find six sources of information about tuberculosis healthcare in the Cape Town area. In order to speak with these six people, it took countless phone calls, emails, and messages. Under a strict time constraint, it became apparent that I would have to work quickly to finish my independent study project, which increased my focus and efficiency while working.

During a very busy time for most organizations and professionals, I was lucky to be able to sit down and speak with those that I could. I had few contacts in South Africa, but through the program directors and persistence, I was able to find great sources for information.

This study may also be somewhat limited by the sensitive nature of the topic. Tuberculosis is a disease that has taken many lives and effects people in many facets of their lives. Conversations about such topics can be difficult to conduct in a constructive manner. That being said, all research participants were more than willing to share their experiences and opinions on the disease.

Literature Review

The vast amount of literature found about tuberculosis (TB) can be overwhelming. Through careful reading and analysis, important background about the disease can be found, and important aspects of lack of access to care can be explored and compared to what is found through field research. These few articles show that there are very apparent hindrances in the implementation of and access to adequate tuberculosis care, however the problem still exists so further study and analysis is needed.

In Zambia, a research group looked at barriers in access to effective tuberculosis care by focusing on adherence to treatment. In order for TB care to be effective, patients have to stick with the medication for a long period of time. When there is low patient compliance with the administered regimen, it hinders effective health care. A descriptive study was done using a sample of 104 patients at a chest clinic in Lusaka who all had pulmonary tuberculosis. All of the patients underwent 4 interviews focused on demographic, knowledge, attitude, and compliance. The results of the study showed that there was a positive correlation between knowledge of TB and attitude, so if patients knew more about their TB, they had a better attitude about it. Additionally, there was a positive correlation between attitude and compliance (Mweemba, Haruzivish, Siziya, Chipimo, Kylike, & Johansson, 2008). This means that patients were more likely to comply with their treatment regimen if they had a better attitude about their illness. In contrast, there was no correlation found between knowledge and compliance meaning that it may not affect how well patients stick to their medication (Mweemba et al., 2008). These findings are vital in justifying the importance of the role that the patients themselves have in their treatment. The research also highlights the role that health care provider could adopt, as improving patients attitudes toward their illness increases their compliance with the TB treatment (Mweemba et al.,

2008). This source gives an international aspect of similar questions about places for improvement in tuberculosis health care.

The BMC Health Services Research journal article gives insight into some of the barriers in access to care in South Africa. More specifically, a large (1446 individuals) was done in a rural area in Mpumalanga province. Using a combination of surveys and case study questions, the research group was able to pin point barriers in access to health care for chronic illness (tuberculosis (TB), HIV/AIDS, diabetes, etc.) through affordability, availability and accessibility. The research suggests that there when families have a lower income, they find it more difficult for get treatment for their illness, and with many families having an unstable income, their treatment is unstable as well (Goudge, Gilson, Russell, Gumede, & Mills, 2009). In rural areas, medications and adequately staffed clinics are not always available for the community. As a result, patients with TB may have to interrupt their medications if the clinics run out, or they may not be seen by a health care professional if there is not one available at the time that they visit the clinic. This lack of availability contributes as a barrier in access to health care for those afflicted by tuberculosis. Lastly, the acceptability of health care was explained as a barrier by the research group. Unacceptable health care is one that has a large distance between health care professionals and their patients. If patients are not well tended to and informed by their health care provider, this causes a lack in effective communication between the two. A lack of effective communication contributes to disease mortality in Mpumalanga because in often leads to misdiagnosis or lack of diagnosis of a patient (Goudge, et al., 2009). This article strengthens the argument that there are many instances of barriers regarding TB care access and implementation.

The journal article written by Dick & Lombard (1997) actually looks at two clinics in Cape Town and accesses patient adherence to TB treatment as it is effected by a health education project. In Clinic A, a health education project was implemented that worked to empower and motivate its patients to stick with their treatment (Dick & Lombard, 1997). The project included an interview with a nurse who was trained in communication techniques when the patient was first diagnosed. Patients at Clinic A were also given a photobook after the interview with materials in it to help keep them on track (Dick & Lombard, 1997). In Clinic B the education plan was not implemented. The results showed a significant increase in adherence to TB treatment regimens when the health education initiative was implemented in Clinic A (Dick & Lombard, 1997). This article shows the impact of the health care provider's relationship with the patient and their role in engaging the patient to ensure treatment success. One of the barriers in access to effective treatment is patient adherence and Dick and Lombard give further insight into how health education may help break down this barrier. This article gives a different research methodology that is more invasive as it deals with the patients themselves, but it further agrees with the argument that there are discrepancies in TB health care.

Tuberculosis knowledge in many communities is not where it should be. In a study done in a rural area of South Africa, a few researchers from the University of the Witwatersrand examined beliefs about TB from both patients and community members in hopes of finding the implications they have on health services and treatment adherence (Edington, Sekatane, & Goldstein, 2002). Through a series of focus groups and individual interviews, the researchers were able to gather valuable information about the general knowledge of TB in the village. This study is an interesting contrast to the previous study about HIV knowledge because it seems that TB knowledge was less when the results are compared with the college students. In the rural

village, “Spread of disease is considered part of social dynamics rather than due to spread of germs” (Edington et al., 2002, p.1080). This description aligns with the results of the study, as the population of South Africans believed that there were 2 types of TB, one that comes from neglecting cultural rules, and a western type of TB that comes mostly from bad habits such as smoking (Edington et al., 2002). Clearly, knowledge about tuberculosis in this part of the country was not conducive to taking the appropriate treatment and precautionary measures for such a serious disease. Some people were afraid of being accused of sleeping with a woman who had recently miscarried (culturally wrong), deterring or delaying them from getting treatment if they were experiencing TB symptoms (Edington et al., 2002). Through more education from health care professionals and community workers, those living in this area would hopefully understand that TB comes from bacteria, and not from breaking cultural rules or drinking too much alcohol. This article also brings up the stigmas that come with tuberculosis. According to Edington et al. (2002) there is “… the knowledge that there is a relationship between breaking rules about sexual behaviour and TB causes shame and guilt” (p. 1079). Since tuberculosis was mostly seen as a disease of bad behaviour, poverty, and recklessness, there are few places, if any, where people could discuss their concerns. This study took into account tuberculosis knowledge as a barrier in access to care.

Salla A. Munro and her colleagues wrote a review on adherence to tuberculosis treatment after extensive amounts of research. They looked at 44 different articles that discussed patients’ and health care providers’ perceptions of adherence to treatment (Munro, Lewin, Smith, Engle, Fretheim, & Volmink, 2007). The researchers combed through the many articles for commonalities in TB treatment compliance. The eight major themes found were: “organisation of treatment and care; interpretations of illness and wellness; the financial burden of treatment;

knowledge, attitudes, and beliefs about treatment; law and immigration; personal characteristics and adherence behaviour; side effects; and family, community, and household support" (Munro et al., 2007, p. 1025). They then boiled these 8 themes down to 4 factors that work together to affect TB treatment compliance: structural factors i.e poverty discrimination; the social context; health service factors; and personal factors (Munro et al., 2007). Each item on these lists was explained in detail using examples from multiple sources and the goal was to help development of program that can enhance adherence to the tuberculosis drug regimen. The overall tone of the review was one that stressed the complexities that come with sticking to a drug regimen for long periods of time. Munro et al. (2007) suggested "interventions that focus on sharing decisions about interventions or the management of health problems with patients and that view the patient as a whole person who has individual preferences situated within a wider social context" (Munro et al., 2007). This was their way of trying to improve the current lack in access to effective care. This article was a sort of synthesis of the many articles in this review, but it did not bring about any new ideas about the reasoning behind lack of access to effective tuberculosis treatment.

Overall the literature found showcases the major implications that TB has on both the global population and South Africa's population. The articles identify many factors that act as barriers in access to and implementation of TB care, and some suggest methods to eradicate these hindrances. These sources can be used to support the study's argument and guide the exploration of barriers that have yet to be uncovered.

Methodology

Mixed methods were used to explore barriers in access to tuberculosis treatment in Cape Town. The wide range of people contacted for information called for these varied methods. I conducted four face to face interviews, used one questionnaire, and conducted one phone interview. In addition to this, I observed the goings on of two clinics, and attended a seminar lecture entitled: 'Perceptions of and Knowledge about tuberculosis (TB): findings from the South African National Health & Nutrition Examination Survey I' at a local medical school. The face to face interviews were the preferred method of information gathering, but the questionnaire and the phone interview were requested by two of the participants. A guiding questionnaire which consisted of 10 questions was used during the interviews to help keep them on topic and make the participants feel more comfortable since it showed prior preparation. The questions were carefully crafted in order to create as much space as possible for the input of the participant. The interviews were recorded using a voice recorder and notes were taken in a notebook.

In addition to the information gathered from various people in the Cape Town community, I also observed two township clinics in Cape Town, and attended a lecture about tuberculosis. These sessions were on the 22nd of November, and they gave me information about the situation that a prospective patient faces upon walking into a clinic looking for treatment. I also got to see and hear some of the health educators that give seminars in the crowded waiting rooms of the clinics. The lecture was entitled: 'Perceptions of and Knowledge about tuberculosis (TB): findings from the South African National Health & Nutrition Examination Survey I" and it was given by public health researchers at a local university.

Participant Profiles:

The first interviewee was conducted face to face on the 12th of November with Jessica Sandile a representative from a local NGO that deals with TB and HIV healthcare, treatment, diagnosis, and community involvement. Jessica was a supervisor that looked after the community care workers. Mrs. Sandile was interviewed in the large township Philippi, at a health care facility. The interview took place in the clinic in an empty meeting room. This interview was recorded and informed consent was given. Jessica was interviewed because she had experience dealing with TB stricken populations and had counselling skills that she often used to work with her patients. She knew, through her work, what TB patients from townships experience when trying to access healthcare. Interviewing Jessica gave support for the idea of traditional healers playing a role in township residents getting treatment for tuberculosis.

The second interview was a phone interview conducted on the 20th of November with Ben Wilson, a trained doctor, public health specialist, and medical school lecturer who directs an organization which educates the community about protecting health care workers from TB. Dr. Wilson was interviewed over the phone after receiving a copy of the guiding questions, and giving his informed consent. Dr. Wilson gave support for the improvement of TB healthcare by improving primary health care, and also supported the improvement of non-health factors that affect TB healthcare such as socioeconomic status and education. Ben Wilson was chosen because of his extensive public health knowledge and his status as being cured from the TB he contracted while treating TB infected patients in the Eastern Cape. He is a testament to the possibility that TB can be cured and most can live a normal life if they take the medication as

instructed. Ben was also able to give first hand details on his suggestions for the improvement of TB healthcare from the prospective of an educated survivor.

The third interviewee was Kevin Moboko from Langa Township. I knew Kevin during my homestay in Langa, so it was a very relaxed interview which allowed for an easy flow of conversation. Kevin was interviewed on the 22nd of November and he gave his consent for the recording of his interview. Kevin had a cousin from the Eastern Cape who had tuberculosis and came to stay with him in Langa in order to receive treatment at the clinic. Kevin Moboko was able to add an interesting view on traditional healers and their role in TB treatment. Having grown up in the Eastern Cape but lived most of his life in Langa, he knew many people who had suffered from both tuberculosis and HIV/AIDS and some of the troubles they had getting diagnosed or treated.

The fourth interviewee was Amelia Anderson, a former HIV/AIDS educator, a PhD candidate, and a mother of a child who was exposed to drug resistant tuberculosis in school. I chose to interview Amelia because she came from a middle-class, white background and she understood the affect this had on her son's TB healthcare and prophylaxis. Our interview took place on the 24th of November at a coffee shop in Observatory. Informed consent was given and the interview was also recorded. Amelia's interest in and knowledge of social justice also provided insight on some of the social barriers one may experience in terms of their accessing TB healthcare such as stigmas and racial differences.

There was one questionnaire that was given by email to Frank Malanda. Dr. Malanda is a trained doctor from the Democratic Republic of the Congo, whose research interest is in health systems ad services, focusing on TB in rural and under-served areas. He is currently lecturing

and researching at a local medical school. I met Frank Malanda in person at his institution on the 14th of November and he gave a lot of ideas and insight on aspects of TB care in Cape Town. He signed the consent form electronically and filled out a TB questionnaire containing the guiding interview questions.

My last interview was conducted on the 27th of November with medical doctor and public health specialist Dr. Arnold Van Dette. I met Dr. Van Dette at a local medical school and we spoke about many different aspects of TB in Cape Town. I chose to interview Dr. Van Dette because his wife contracted MDR-TB and he was able to speak about their healthcare while she was getting treatment. Arnold Van Dette added a wealth of information about drug resistant strains of TB, and also added his own opinions on the historical impact on tuberculosis healthcare.

Finally, the inclusion of secondary sources was crucial to this project. Past literature gives the reader a crash course in tuberculosis general knowledge, which helps explain some of the complexities of infectious disease. The literature chosen helps ground the study. It shows the importance of TB healthcare as a global issue, an issue in South Africa, and as an issue in Cape Town. Additionally, the literature shows support of some of the subtopics that all fall under barriers in access to care. Traditional healers, stigmas, socioeconomic factors, HIV/AIDS, and drug adherence are all discussed by previous researchers and add supporting, contrasting, or topic expanding information.

In terms of weaknesses, the clinic visits could have been more productive if I was able to speak with some staff about the workings of the clinics. Observations do go a long way, but some concrete information would have added to my research. My mixed methods study did lack

a form of repetition because I did not receive all of my information in a uniform way. This can be both a strength and a weakness. As a strength, the interviewees were able to use their preferred method of contact, as some professionals were too busy to meet face to face. Conversely, when a questionnaire is filled out through email, it does not leave much room for extra bits of information or anecdotes and there can be no analysis of body language. This distance between the interviewer and interviewee can decrease the personal insights one can get from being face to face with the participant.

Glossary

AIDS: Acquired Immune Deficiency Syndrome

ART: Antiretroviral Therapy

DOTS: Directly Observed Treatment (short course)

HIV: Human Immunodeficiency Virus

Igqirha: Xhosa traditional healer

NGO: Non-Governmental Organization

MDR-TB: Mutli-Drug Resistant Tuberculosis.

Sangoma: Traditional Healer

WHO: World Health Organization

XDR TB: Extensively Drug Resistant Tuberculosis

Findings and Analysis

The Struggle for the Spotlight: TB vs. HIV/AIDS

Tuberculosis is the leading cause of death in South Africa (Cramm, Finkenflügel, Møller, &Nieboer, 2010). That being said, the TB epidemic has continually been underrepresented in the public eye when compared to the HIV/ AIDS epidemic. South Africa has the highest numbers of drug resistant TB and the second highest number of new TB cases in the world (WHO, 2014). This fact shows the need for more research and exploration of the TB epidemic in South Africa. Additionally, over 70% of those who are infected with TB are also HIV positive (WHO, 2014). While both diseases are extremely important and deserve attention from the public, the TB epidemic has not had the same kind of public awareness and support that HIV/AIDS has. According to Ngamvithayapong, Winkvist, & Diwan, (2000), although public awareness about AIDS has increased, there has not been the same amount of increase in terms of tuberculosis public awareness. This is an alarming finding because of how closely the two diseases are related. The TB epidemic is highly driven by the HIV/AIDS epidemic, because "TB adds to the illness burden of HIV-infected patients and shortens their life expectancy, while the HIV epidemic stimulates TB spread" (Ngamvithayapong et al., 2000). When interviewing Frank Malanda, trained doctor and researcher from the Congo, he explained that HIV patients are more likely to get infected with TB because it is the most prevalent opportunistic infection (F. Malanda, personal communication, November 14, 2014). Some ISP participants expressed similar thoughts about the differences between TB and HIV/AIDS in Cape Town. Dr. Ben Wilson brought up the fact that there were some quite wealthy and outspoken people who contracted HIV that were able to access media and funding to make a big deal about the disease.

"HIV advocacy is different than TB advocacy which is kind of voiceless," Dr. Wilson remarked. He also expressed that HIV has a much more harrowing picture associated with it and that TB does not have that same picture. (B. Wilson, personal communication, November 20, 2014). Dr. Wilson's sentiments make sense and show from the perspective of a former clinician and current researcher that TB is on the back burner in Cape Town. When speaking to Amelia about the differences between HIV/AIDS and TB, she stated that she thinks that HIV/AIDS research gets more funding, and that TB is mostly talked about in its relation to HIV. Amelia called attention to the fact that the lumping together of both epidemics is detrimental to TB health care and treatment, because some people feel that TB can turn into HIV, or vice versa. (A. Anderson, personal communication, November 24th, 2014). The research clearly indicates the discrepancies between public awareness and activism between TB and HIV/AIDS, which in itself acts as a barrier to accessing effective TB care although there is evidence of the importance of controlling both epidemics in Cape Town.

Another aspect in which HIV/AIDS reaps the benefit of increased public knowledge and awareness is in the drug market itself. For many people who have HIV, they are able to take one tablet a day and live a mostly healthy lifestyle with minimal side effects. In the case of tuberculosis, there are a range of side effects ranging from nausea to hearing loss that sometimes can plague those trying to complete the six month regimen (Daftary, Padayatchib, & O'Donnell, 2014). According to this same study which researched HIV positive patient adherence to XDR-TB drugs:

> The greater perceived tolerability and lower pill burden of ART… funnelled patients' adherence towards ART and against XDR-TB treatment. Another driver appeared to be patients' personal commitment to adhere to ART. They had attended education and counselling sessions prior to initiating HIV treatment. They had been taught that antiretrovirals were 'strict with time' and felt

> accountable for taking the prescribed doses. Adherence to XDR-TB treatment, in contrast, was considered to be the responsibility of the administering nurse, who controlled when and how patients received their daily dose. (Daftary et al., 2014, p. 1110)

These results show that in this region of KwaZulu-Natal, it was clear that TB treatment was seen as less important than treatment for HIV, showing the need for increased public knowledge of the severity of TB, especially in its MDR and XDR strains. The evidence from this study also calls into question the efficiency of implementation of the DOTS program suggested by the WHO in combating the TB epidemic. The ISP evidence suggests that the TB control program focuses on the health care professionals and not enough on patient motivation for taking the TB drugs. Kevin Moboko from Langa also explained that he thinks the TB drug regimen is long and difficult to keep up (K. Moboko, personal communication, November 22, 2014). Dr. Van Dette also spoke about the importance of TB awareness in the scope of HIV/AIDS and other infectious disease epidemics:

> [We are] Breaking our heads about it. TB is the old foe... it is like the familiar step child. The perception is that it is under control. There is a complacency regarding TB. We need to break that perception. We are trying to reawaken people to know that if you breathe you are susceptible. (A. Van Dette, personal communication, November 24, 2014)

Dr. Van Dette fearlessly described his opinion of public perception of TB control. In regards to other infectious diseases he said:

> HIV is a new disease that affected people who had education and were very connected. They initially faced stigma but they knew how to move funds... In South Africa the HIV epidemic was a disaster. Ebola is the new kid on the block. We are trying to rebrand [TB] because it has become drug resistant. It is a new disease. The XDR cure rate is under twenty percent. (A. Van Dette, personal communication, November 24, 2014).

The research communicates the need to bring TB into the spotlight. The competition between TB and HIV/AIDS makes sense as both ailments are in need of serious intervention, but the fact that tuberculosis kills the most people in South Africa *and* the most HIV related deaths in South Africa are due to TB speaks volumes about its importance. In Cape Town specifically, there are relatively less cases of HIV/AIDS, but the tuberculosis numbers are still relatively high (A. Van Dette, personal communication, November 27, 2014). Tuberculosis stands out in the Western Cape and Cape Town as a serious threat, and those who need health care for this ailment face many barriers. HIV/AIDS also attaches more stigmas to TB in Cape Town.

Stigmatization of Disease

The relationship between HIV/AIDS and TB also acts as a barrier in access to care because of the stigmas associated with both of these diseases. HIV/AIDS is a sexually transmitted disease which has its own stigmatization as a disease that affects those who have been sexually promiscuous and irresponsible which is far from the truth. In one study, it was reported that 60% of subjects believed that TB turns into HIV, meaning that TB stigmatization would be compounded by HIV stigmatization (Daftary et al., 2014). Kevin Moboko from Langa Township has experienced that: “Even if somebody doesn’t have HIV, the moment someone shows symptoms of TB, like they get skinny, they are afraid to go and get treated because of what others will think” (K. Moboko, personal communication, November 22, 2014). If public opinion concludes that someone with TB will eventually develop HIV, or that they already have HIV, that would instil more fear in someone suffering from TB and may hinder them from seeking treatment.

Stigma associated with infectious disease can hinder health care tremendously on many different levels. When a disease or ailment is stigmatized, it becomes difficult for those who are

openly infected, to live a normal life in society. People may begin to develop negative opinions of those who are infected and many times irrelevant or untrue stereotypes about the ailment can surface (Tewksbury & McGaughey, 2010). Furthermore, stigmatization of a disease or ailment can hinder effective healthcare due to lack of treatment or treatment delays. If someone is experiencing symptoms of a stigmatized disease, they may not want people to know what is going on out of fear or embarrassment, and consequently do not get treated right away or at all (Courtwright & Turner, 2010). In some cases, when people decide to go for treatment but do it in secret, they miss out on the familial support and encouragement that can help treatment success and ultimately facilitate recovery. In terms of tuberculosis, there are many stigmas surrounding the disease that can hinder access to effective healthcare. According to Courtwright & Turner, 2010: "Substantially less study has been conducted on the mechanisms through which stigma impacts the health of individuals at risk for or infected with tuberculosis" (Courtwright & Turner, 2010, p. 35). Literature shows that there are socioeconomic consequences of TB related stigma. For example, the isolation that can come from a stigmatized disease can affect one's opportunity for finding work. If coworkers do not want to be around somebody who suffers from active TB, it would be difficult to find a job or a career (Courtwright & Turner, 2010). Clearly this hinders access to TB care further because a lack of income can decrease one's ability to afford going to the clinic or to the pharmacy for treatment. Sufferers of tuberculosis may also feel an overwhelming sense of guilt due to stigmatization of the disease. There are notions out there that say that TB is a disease of those who are dirty and have partaken in an act the subjected them to the infection, such as drinking or smoking (Edginton, Sekatane, & Goldstein, 2002). When public knowledge places a TB sufferer in a bad light, it hinders effective treatment. An uplifting and accepting environment would provide a safer space for those who are sick to

seek help and start their healing process. The research suggests that ISP study participants also felt similarly about the detrimental effects of stigmatization on accessing effective TB healthcare. Dr. Ben Wilson, TB survivor himself speaks about stigmatization:

> We have to really, um, get the um voice out there that every normal healthy person, as long as they breathe, they are vulnerable". Until we can change that perception, we really have difficulty to on the community level, to change the epidemic. (B. Wilson, personal communication, November 20, 2014).

Dr. Arnold Van Dette, who dealt with his wife's multidrug resistant TB, stresses the impact of stigmatization on tuberculosis health care: "It is the stigma that drives us" (A. Van Dette, personal communication November 27, 2014). He explains that when one has TB there is an overwhelming assumption that that person has done something wrong, or that something is wrong with them. Dr. Van Dette also describes different types of discrimination that arise from the different stigmatizations. Direct discrimination includes those wrongful actions of others towards an infected person that affects that person's life (A. Van Dette, personal communication November 27, 2014). For example if an employer finds out that his employee had tuberculosis, and then fires him instead of supporting him and his treatment. This discrimination is reminiscent of the discrimination seen in regards to things like race, class, and gender (A. Anderson, personal communication, November 24, 2014). This is a barrier in access to effective care if individuals are in fear of losing their job if they are honest about their infection. This breeds a culture of secrecy surrounding TB, with can unfortunately close the door on open discourse about TB which could potentially decrease the isolating feeling of disease stigmatization. There is also indirect discrimination associated with tuberculosis. TB is being associated with many other ailments these days as the biomedical scientists continue their research. There are studies that link TB to other things such as diabetes, smoking, and

malnutrition (A. Van Dette, personal communication November 27, 2014). One may not want to go for TB treatment if they think people will assume they are malnourished or have other diseases, hindering access to effective care. Disease stigmatization is a barrier n access to effective tuberculosis care in Cape Town that weakens disease control.

Traditional Healers: Sangomas, Igqirhas, and the 'Others'

The role of traditional healers in access to TB healthcare has been a controversial issue, and research affirms this fact. The World Health Organization defines traditional medicine as: "…practices, approaches, knowledge and beliefs incorporating plant, animal and mineral based medicines, spiritual therapies, manual techniques and exercises, applied singularly or in combination to treat, diagnose and prevent illnesses or maintain well-being" (WHO, 2008) . In South Africa, a large percentage of the population first visits traditional healers who practice traditional medicine. These numbers are also increasing as the number of traditional healers rise in South Africa (Campbell &Amin, 2014). The role of traditional healers in TB healthcare has not been extensively researched, but many studies have described traditional healer visits as a delay to effective tuberculosis diagnosis and treatment (A. Van Dette, personal communication, November 24, 2014). In one study, fourteen percent of TB suspects in Manenberg, Cape Town, had visited a traditional healer before going to the hospital. This study classified visiting a traditional healer before diagnosis by a clinic, as a patient delay to diagnosis (Meintjes**,** Schoeman Morroni, Wilson**,** & Maarten, 2008). Another South African study highlighted that a quarter of their respondents visited a traditional healer before visiting the clinic for TB. One of their respondents gave their reasoning for this and expressed that the hospital will delay them so it is better to begin with the traditional healer (Edington, Sekatane, & Goldstein, 2002).

ISP study participant, Dr. Arnold Van Dette stated his opinion of the competition between traditional and westernized medicine in TB: “Historically both groups see each other with suspicion. Instead of engaging, we have managed to antagonize each other” (A. Van Dette, personal communication, November 27, 2014). Jessica Sandile, ISP participant from a local NGO that deals with tuberculosis healthcare cited traditional medicine as the most pressing barrier in access to TB healthcare. As a community care worker supervisor, she is aware of the goings on inside clients’ homes as a part of the home visits that uphold the DOTS Programme as recommended by the WHO. Mrs. Sandile comments:

> If I have no appetite, it’s a symptom of TB. Instead of going to clinic to check TB I am going to the sangoma to give me something to clean my body and my stomach so that I can have appetite”. When my weight picks up, the meds will not cure TB. We grew up with traditional meds. The clinics are new you see …That’s why you find people coming to the clinics very sick…They were feeling sick before but they were going to the sangomas, paying money, whereas this thing needs the clinic. (J. Sandile, personal communication, November 12, 2014)

Mrs. Sandile’s experienced opinion provides insight into the ongoing struggle between traditional healers and westernized health care providers. One of the doctors that participated in the study suggested a different way of assessing the traditional healer’s role access to TB health care. Dr. Wilson recognized that traditional healers play an important role in the way people seek health care in Cape Town, as they are often the first people that others contact if they are feeling ill. If the traditional healers do not recognize an ailment as TB, that might postpone their diagnosis or referral which may cause the disease to get worse (B. Wilson, personal communication, November 20, 2014). Dr. Wilson realizes that it may be a barrier, but did not assume the traditional healers were in the wrong: “Maybe our health care services are not

culturally accepting enough for those who feel they need to see a traditional healer" (B. Wilson, personal communication, November 20, 2014). This was an extremely important point that no other participant brought up- it is essential that traditional healers and westernized medicine try to complement each other. Both Dr. Van Dette and Dr. Wilson agreed that many health care providers do not know much about the influence of traditional healers on TB health care. Dr. Van Dette also stated that he was "less of an issue in the Western Cape" but recognized that it was a part of Xhosa culture. He warned about another aspect of traditional healers in Cape Town: "There are lots of people out to make a quick buck here. They do a lot more harm than good" (A. Van Dette, personal communication, November 27, 2014). This is an interesting point because some of the traditional healers may not be traditional healers that have gotten their ability from ancestors. This type of fraud can create a large barrier in accessing care to TB suspects because the 'traditional healer' may not know more about medicine than anyone else, leading any potential TB suspects further away from treatment. Kevin Moboko of Langa Township did not agree with the argument that traditional healers hinder access to effective TB healthcare and defended their ability to diagnose and treat TB. He explained that the *igqirha* can be better equipped at healing the root cause of disease, as opposed to the western way of healing the symptoms (K. Moboko personal communication November 22, 2014). Kevin's opinion adds a refreshing contrast to the sentiments that other participants had about traditional healers, although he also highlighted the fact that there is some integration of the two types of medicine (K. Moboko personal communication November 22, 2014). According to the research, many people in Cape Town consult traditional healers for medical advice, some of whom are not equipped to diagnose or treat tuberculosis, hindering access to effective healthcare.

More Money, More Access: Socioeconomic Factors

Socioeconomic factors affect access to tuberculosis treatment and healthcare. The most referenced by participants among the long list of socioeconomic factors that can hinder access to efficient TB healthcare were income and housing. The research suggests it costs money to have tuberculosis in Cape Town. Although most people can get their drugs and diagnostics for free, there are costs associated with traveling to these clinics or hospitals. In order to take a taxi or a minibus, income plays a role. If someone who suffers from TB does not have the money to get to the pharmacy, chances are they will not be able to pick up their medication. This is a pressing matter because of the importance of sticking to antibiotics and not skipping days. Tuberculosis is a bacterium that replicates in the body over time and every day counts when trying to kill the bacteria (Dye, 2006). Income also plays a role in terms of work. Those who are dependent upon money from working to help take care of their families or loved ones may not be able to take a few hours off of work in order to get to the doctor for a check-up or treatment. For some people, it comes down to making a few more dollars, or going in and getting a TB test. Dr. Wilson's sentiments seemed to focus on economic and monetary influence on TB health care. He remarks: "You might go to work to buy food for this evening instead of thinking about your health in the long term" (B. Wilson, personal communication, November 22, 2014). This view supports the argument for the impact of income on tuberculosis healthcare. This is issue is a reality for many of those living in Cape Town, a city with a large gap between the rich and the poor. Where one lives can also act as a barrier to effective tuberculosis health care in Cape Town. The difference between living in richer or poorer area influences access to TB healthcare. TB symptoms include tiredness and weakness, and proximity to public transport and public health services can affect

one's ability to seek treatment. Also, the different housing conditions can hinder effective treatment. Someone living in a crowded shanty with poor ventilation, in an environment that perpetuates lower immune system function, would have a harder time beating the disease than one who lives in an area that is more sanitary and conducive to healthy living (B. Wilson, personal communication, November 22, 2014).

Most literature that discusses the influence of socioeconomic factors on health speaks about its influence on treatment adherence, rightfully so. It is important to express the connection between treatment adherence and TB healthcare. Due to the long haul that is the treatment regimen for any form of tuberculosis, when the flow of treatment is interrupted, effective healthcare is hindered. According to Lutge, Lewin, Volmink, Friedman, & Lombard (2013), poverty decreases the adherence to TB treatment. After a 120 rand voucher was given to their study participants each month however, the adherence to treatment did not increase significantly. These results may suggest that there are other factors that work in addition to economic factors that can inhibit treatment adherence.

Some of the ISP participants brought up socioeconomic factors that they felt hindered access to effective tuberculosis care. Mrs. Sandile said: "The treatment must be nearer for the people. If someone has TB, that person is very weak. If there is a clinic nearby, it would be advantageous" (J. Sandile, personal communication, November 12, 2014). This response shows that in townships, the long distance that some have to go in order to get to a facility for testing and treatment may decrease implementation of effective care. Dr. Malanda expressed his concern for the poor in terms of their access to care. He explained that often times they face economic, geographic, and public health complications because they are from poor communities (F. Malanda, personal communication, November 14, 2014). Amelia Anderson made many

comments on the effects of the socioeconomic disparities in Cape Town's effect on TB treatment. In her situation, she had a wealth of resources that she could consult if she had questions about her son's TB prophylaxis. Access to internet, knowing people who are health care professionals, and having a car to get to the hospital were all things that she cited as helpful to her son's treatment adherence. When it came to TB screening, she was able to afford two additional tests other than the free skin test offered by the public clinic. (A. Anderson, personal communication, November 24, 2014). Some of these resources are not available to many of those seeking treatment and diagnosis, and may stand as barriers to effective healthcare. Participants also gave their opinions on the causes of these socioeconomic barriers that exist. South Africa's history and its resultant disparities were the main causes for socioeconomic barriers that the research suggested. Kevin Moboko says: "In the old dispensation, I think it was difficult to get treated, unless you were white, then you would get all the support. Today there is a lot of support. In the old dispensation they would not have done that." (K. Moboko, personal communication, November 22, 2014). Dr. Ben Wilson attributed this barrier to history and HIV/AIDS spotlight:

> Health care systems were not built to adequately treat TB because it started in the poorer populations. The system takes a while to change. They are only now starting to build hospitals in Khayelitsha. In general, TB didn't, uh, get the attention it deserved compared to other diseases specifically with HIV. It's the biggest killer but everyone knows about HIV and TB is going under the radar. (B. Wilson, personal communication, November 20, 2014)

Dr. Van Dette had similar sentiments, but cited more specifically apartheid legislature and race relations:

> Through the degradation [of apartheid], people were forced into unnatural environments. People were forced to live in crowded areas. Impoverished them and made them more susceptible to diseases like TB. Also, mine work played a big role. If you're working in mines you are more susceptible to get TB because of the dust in your lungs and there is no ventilation. People are also forced to be away from their families in over-crowded area. (A. Van Dette, personal communication, November 27, 2014).

This reasoning for the socioeconomic barriers relates the country's history of mining and racial discrimination to hindering of TB treatment for some. These socioeconomic barriers spill into the impact of the public health sector on access to TB healthcare.

Not So Public Health

The Western Cape provincial government adopted the DOTS Programme to combat the tuberculosis epidemic. As a part of this, clinics and three NGOs (TB Care Association, Santa Cape Town and Santa Western Cape) work in communities to try and motivate patients to adhere to their treatment plan for six to eight months. Volunteers also act as support for those in communities on treatment plans, and they refer TB suspects to clinics as needed The TB Control Programme in the Western Cape has set to out identify eighty percent of TB cases in the province and start those people on curative treatment plan(TB Control Programme, 2014). Public health initiatives all over Cape Town work to help gain control of the tuberculosis. Despite the aforementioned efforts, TB is still a large problem in the province, suggesting that successful implementation could use some improvements. This project shows the most prevalent public health issues that challenge access to TB health care are clinic waiting times, poor referral system, and patient issues with the treatment regimen.

Study participant Amelia Anderson made a few remarks about the public health system in the area. She explained that the system here is probably one of the best ones in the country. That being said, she explained that although she normally does not use the public health system, she hears the story all the time. “You go and you just wait and wait and wait” (A. Anderson, personal communication, November 24, 2014). In getting treatment for her son who was exposed to TB by a teacher, she used the public clinics and experienced them running out of the drugs twice in about a two month period (A. Anderson, personal communication, November 24, 2014). Mrs. Anderson is in a place where she was able to drive to a pharmacy and buy the drugs that her son needed. For a large number of those looking to get TB meds for free, they would have been out of luck. When the clinic run out of drugs, most people are forced to wait until a restock, and thus cannot take their meds until this time. This is a public health problem because it decreases patient adherence to treatment and in turn decreases effective TB health care. Also, it delays the goals of the TB Control Programme.

The treatment regimen has been heavily cited as a public health issue that is a barrier in access to effective TB healthcare. For treatment susceptible tuberculosis, the treatment regimen has been criticized as being too long for the patients to stay motivated. This is important because poor regimens are also a cause of treatment defaulting. Jess Sandile explains:

> The main thing I saw is they become tired of taking meds. They are tired but they feel well. To help defaulting it’s very difficult, even when I am sick it’s hard to finish antibiotics that are five days. We don’t know that we must finish the course of the treatment even if you feel well. (J. Sandile, personal communication, November 12, 2014)

Dr. Van Dette defended Cape Town's public health structure, but felt that implementation was lacking:

> There are lots of resources directed at TB. The health care is good, but they are not making a dent in it. Those reasons are not really understood. We need community based interactions to address this. Our focus has been very biomedical. (A. Van Dette, personal communication November 27, 2014)

This view mirrors the argument that changes need to be made in order public health sector to decrease the challenge in accessing effective tuberculosis healthcare. In Cape Town, the research suggests that most public health facilities are adequate, but the public still struggles to achieve unwavering TB care.

What Now: Possible Solutions

Barriers in access to tuberculosis healthcare are no strange concept in Cape Town. South Africans living in this area live in this reality every day, no matter what end of the socioeconomic totem pole they come from. Despite this, it is important to explore what the people think can be done to improve the status of the TB epidemic. The research participants were given the space to speak on what they felt, if anything, should to be done in order to improve TB healthcare in Cape Town. Governmental assistance was cited as a possible solution for increasing access to effective TB care in Cape Town. Jessica from a local NGO suggested that the government give funds for mobile clinics that go into communities for treatment. She stated that there are some for testing, but the treatment is too far for most of her patients (J. Sandile, personal communication, November 12, 2014). Dr. Malanda said: "Access to TB healthcare should be declared a human right. TB is preventable, treatable, and curable despite

being among people for centuries" (F. Malanda, personal communication, November 14, 2014). Dr. Malanda is suggesting an approach that comes more from legislation in hopes that it will influence public action. Amelia also called upon the government and felt that if the government "did what they said they would do about housing and sanitation that would help immensely" (A. Anderson, personal communication, November 24, 2014). Both Kevin Moboko and Dr. Ben Wilson defended the government because of their approval of the actions of the Minister of Health, Theuns Botha. Wilson commended the Minister's actions and said the he is doing a "…fantastic job by going out into the communities" (B. Wilson, personal communication, November 20, 2014). Kevin was especially pleased by his stance on decreasing tobacco usage, and agreed that he is doing great things to push legislature to decrease smoking, which makes one more susceptible to TB (K. Moboko, personal communication, November 22, 2014).

Another common thread in terms of solutions came in the form of education. As a community care worker supervisor, Jessica Sandile mentioned that people need to be educated about both TB and HIV before they become ill. "Proper education is given to those who are already ill. Those who are not should also have sessions so they can prevent themselves from getting sick. Government only considers those who are infected" (J. Sandile, November 12, 2014). Not only education, but early education is a way to breakdown some of the barriers in access to effective TB care for Mrs. Sandile. Ben Wilson said: "Healthcare education is the main way to stop the spread and raising awareness" (B. Wilson, personal communication, November 20, 2014). Interestingly enough, only two out of six participants stated education as part of their ideas for solutions to improving TB healthcare. When discussing solutions that can enhance adherence to treatment specifically, Jessica Sandile had a lot to say:

> In each area there must be a person coming from the clinic to make sure they are taking the treatments. Some meds are taken at night so no one will be able to check. At least for the first 3 months, once a week is not enough. Some people flush their meds and the community care workers just count the meds they do not watch them take them. (J. Sandile, personal communication, November 12, 2014)

Mrs. Sandile expresses that TB patients need more supervision at the beginning of the treatment regimen in order to stick with their medication. Frank Malanda explained the difficulty in treatment adherence for drug resistant strains of TB. “Treatment of this form is very expensive and takes plus or minus eighteen months, which also increases the risk of defaulting again (F. Malanda, personal communication, November 14, 2014). Dr. Malanda was not the only one to cite the harsh reality of treating drug resistant TB. Dr. Wilson, after explaining the increasing rates of MDR-TB and XDR- TB in Cape Town, explained that the healthcare for these resistant strains is far from decentralized, decreasing access to those who cannot travel for their treatment (B. Wilson, personal communication, November 20, 2014). Possible solutions from this research communicate the need for increased government assistance, education, and an enhancement of treatment implementation to combat the aforementioned barriers in access to care.

As it stands, TB healthcare in Cape Town is a dynamic issue. Study participants gave their educated and experienced opinions on the barriers in access, and possible solutions to the challenges that individuals face in obtaining care. The research demonstrates that there is more to be done in terms of both research and public action, and TB healthcare is representative of other social issues that are prevalent in this area.

Ethical Reflexivity

The research practices and analyses considered ethics carefully. The vulnerable population discussed in the interviews were treated as such. The Health Insurance Portability and Accountability Act (HIPAA) was constantly considered, and both the interview guidelines and the consent form addressed patient privacy and security. All participants were given the option to decline to interview, or decline recording, without penalty. Participants were also assured that any information they did not want to be disclosed, would not be. No specific names, TB or HIV/AIDS statuses were asked and participants were not chosen based on disease status. Those participants that represented larger organisations were assured that their place of work would not be put into jeopardy as all names will be obscured for privacy purposes. To ensure reciprocity, a copy of the transcribed interview was offered to all participants, and they were assured that they would have a copy of the final work upon request.

The power dynamics at play during this research were treated carefully. As a middle-class American student enquiring about two of the largest health issues in South Africa, I was in a place where it was at times easy to come off in a manner that was judgemental. I assured all interviewees and my advisors that the project was purely exploratory, and that I intended to learn from the project. That being said, all research findings and observations were analysed with a critical eye looking for relationships and important information from the raw data. These ethical concerns guided my research and the implications of working in a completely different culture were paid attention to throughout the process. Cultural sensitivity was a main goal as the project progressed because it was important to me to form healthy relationships with all participants.

Conclusion

This study examined the most prevalent barriers in access to effective tuberculosis healthcare. This was important due to the aggressive nature of the TB epidemic in Cape Town, and the implications of the HIV/AIDS epidemic on TB awareness and healthcare. The results show that there were several barriers that were cited by the research participants. The relationship between tuberculosis and HIV/AIDS in fact acted as a barrier to effective TB healthcare due to its overshadowing the tuberculosis epidemic. Stigmatization was another barrier in access to effective healthcare. Tuberculosis stigmatization was compounded at times by HIV/AIDS stigmatization as the two ailments are often grouped together. In addition there were stigmas associated with TB alone that hindered access to effective healthcare. The role of traditional healer was at times seen as a barrier to effective TB healthcare as well, but there were contrasting views communicated by study participants. It was also found that socioeconomic factors such as low income and poor housing can also hinder one's access to TB care if they do not have adequate resources. Lastly, issues with the public health system can also act as a barrier to effective treatment. Hindrances were assessed mostly by lack of adherence to treatment, lack of diagnosis, defaulting, and lack of constructive awareness. Solutions suggested for breaking down these barriers were governmental assistance, education, and community involvement. This project set out to explore tuberculosis in Cape Town with an inquisitive eye, and the results show the need for further study in order to get TB under control in Cape Town, South Africa, and across the globe.

Tuberculosis healthcare showcases the disparities in this country that transcend public health. The country's rich history has clearly left a mark on the wellbeing of its people. The multiculturalism in South Africa is something to be proud of, but with that diversity comes a

challenge of different people living together harmoniously. The reality is that not everyone has access to treat a disease that is plaguing the nation. This communicates just one of the difficulties that a nation that is going through many social changes can face. South African people deserve the unhindered tuberculosis care, and it is time to mobilize for a change.

Recommendations for Further Study

There are many other topics that can be explored to expand upon this research study. It may be beneficial to decipher barriers in access to care as assessed by those of different races. If there were common threads among those of a certain background, it may help health care providers improve patient care. Additionally, working more closely with one NGO specifically, interviewing people that play different roles in TB healthcare from just that organization, may give more strength to the differences in responses because the interviewees would have a more common thread. Another way one would be able to expand this study is by looking at gender roles in healthcare and how that affects tuberculosis diagnosis treatment.

Appendix

Guiding Interview Questions:

Guiding Questions for Barriers in Access to TB care:

1. Tell me about yourself and what you do.
2. Why is TB control an issue of importance?
3. What do you think TB healthcare is like in Cape Town?
4. How do you think TB health care got to be this way?
5. What do you think are the most pressing barriers in access to effective TB care in this area? Please go into detail where possible.
6. For those who can get treatment but end up defaulting, what challenges do they face? i.e., what, in your opinion, causes defaulting?
7. What needs to change in order to increase TB control in this area?
8. What is the government/healthcare provider/South African's role?
9. In terms of HIV/AIDS, where does TB come in to play? How does public awareness differ between the two infectious diseases?
10. Is there anything that I did not ask about TB health care in this area that you think is important to know? Is there something that is commonly left out of the equation that shouldn't be?

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